

### NUFFIELD COUNCIL≌ BIOETHICS

## OVERVIEW OF REPORT FOR HEALTH RESEARCHERS AND RESEARCH INSTITUTIONS

# Research in global health emergencies: ethical issues

#### Published 28 January 2020

The Nuffield Council on Bioethics has published the findings of an in-depth inquiry into the ethical issues relating to research in global health emergencies. The inquiry was run by an international working group which gathered evidence from contributors across the globe.

The report of our inquiry identifies ways that research can be undertaken ethically during emergencies. It presents an ethical compass to guide research conduct at policy level and on the ground, with three guiding values: fairness, equal respect, and helping reduce suffering. A diagram of the ethical compass (overleaf) provides prompts that those involved in the wider research ecosystem should think through.

Several of our recommendations are directed to health researchers and research institutions. We suggest that changes in line with these recommendations would align researchers' and research institutions' practices more closely with our three guiding values. The recommendations include:

- Developing study protocols with local community input to ensure that the proposed procedures are acceptable (recommendation 6);
- Avoiding an automatic exclusion of 'vulnerable groups' such as children or pregnant women, and clearly justifying any exclusion criteria that are set (recommendation 7);
- Reviewing performance management systems in research institutions to ensure mentoring / supporting overseas colleagues is credited (recommendation 13);
- Prioritising research on stakeholders' views of consent and governance mechanisms to create trust and confidence in data and sample sharing (recommendation 17);
- Sharing information (via an inventory held by WHO or a regional centre for disease control) where substantial sample collections are held as part of international research collaborations (recommendation 18);
- Ensuring those working in low- and middle-income countries can access research findings freely (recommendation 20); and
- Considering whether their general employment policies, and employment policies developed for a particular emergency, represent a 'fair offer' for both local and international research staff in the circumstances (recommendation 23).

The full list of our recommendations is published in the long report and executive summary, both available at <u>www.nuffieldbioethics.org</u>. We have summarised these in the following call for action to research funders, governments, and others.

#### A call for action

We want to maximise the contribution that scientifically robust, ethical research can make to improving the health of people affected by emergencies.

We are issuing a call for action to research funders, governments, and others to:

- Ensure that research is not supported unless the basic health needs of research participants are being addressed through the response effort. Research funders will need to work in partnerships with humanitarian organisations and ministries of health to ensure this.
- Invest in putting community engagement mechanisms into emergency research to make them a reality. In the longer term, engagement must be a central part of local healthcare systems to ensure sustainability and preparedness.
- Promote fair and equitable collaborations between research organisations, particularly between external research institutions and their local partners in high- and low-income settings.
- Support emergency planning including securing robust health and health research systems given the vital importance of properly resourced preparedness between emergencies.

#### AN ETHICAL COMPASS TO GUIDE DECISION-MAKING

